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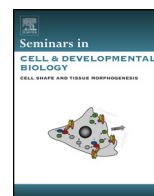




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Review

EuroStemCell: A European infrastructure for communication and engagement with stem cell research

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ABSTRACT

EuroStemCell is a large and growing network of organizations and individuals focused on public engagement with stem cells and regenerative medicine – a fluid and contested domain, where scientific, political, ethical, legal and societal perspectives intersect. Rooted in the European stem cell research community, this project has developed collaborative and innovative approaches to information provision and direct and online engagement, that reflect and respond to the dynamic growth of the field itself. EuroStemCell started as the communication and outreach component of a research consortium and subsequently continued as a stand-alone engagement initiative. The involvement of established European stem cell scientists has grown year-on-year, facilitating their participation in public engagement by allowing them to make high-value contributions with broad reach. The project has now had sustained support by partners and funders for over twelve years, and thus provides a model for longevity in public engagement efforts. This paper considers the evolution of the EuroStemCell project in response to – and in dialogue with – its evolving environment. In it, we aim to reveal the mechanisms and approaches taken by EuroStemCell, such that others within the scientific community can explore these ideas and be further enabled in their own public engagement endeavours.

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Abbreviations: EC, European Commission; EU, European Union.

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1. Introduction

The stem cell research and regenerative medicine sector excites and inspires hope, whilst simultaneously raising new social and ethical concerns. The sector holds promise for developing new treatments, for conditions such as Parkinson's disease, multiple sclerosis, macular degeneration and spinal cord injury. This has led to continued and significant investment from UK and European governments, with expectations that stem cell research will stimulate economic and scientific growth along with health benefits [1]. The enormous public interest in this emergent technology therefore comes as no surprise, but does pose challenges around representation and communication in the public domain, particularly in the context of widespread international media and indeed, some academic hype [2,3].

In the last ten years, www.eurostemcell.org – the centre-piece of a wider engagement project called EuroStemCell – has become one of the world's premier sources of accessible, scientifically credible, up-to-date information about stem cell and regenerative medicine research and related societal issues, in 2016 the website reached a worldwide audience of more than 1.3 million. This leading position reflects careful and intentional development of the project, using a 'bottom-up' approach grounded in dialogic (i.e. reciprocal) engagement with audiences and stakeholders. In this article, we examine EuroStemCell's development, and how its goals, remit and impact have evolved in step with scientific developments in stem cell research. We also share what we have learned about creating space, opportunities and infrastructure for biologists to engage with non-specialists in this fast moving area of science, with the hope that biologists from other fields will be inspired and helped to continue this mandate in their arenas.

2. Introducing EuroStemCell

Stem cell research is a fast moving area of science, which raises fundamental questions about the nature of life and where it begins. It also intersects with society on several levels (e.g. organ/tissue donation, ethics, religion, values, medicine, aging, patienthood). As such there are many interest groups who present strong opinions and perspectives about stem cell research. EuroStemCell is a public engagement initiative that aims to help European citizens navigate this context to make sense of the research and the impact it has on society and people's lives. This encompasses stem cell biology and regenerative medicine in the broadest sense, from basic research to ethical and societal issues. EuroStemCell's core mission, established in 2010, is to *help European citizens make sense of stem cells*. To achieve this, the project has continuously evolved in response to audience demand and evaluation. As part of this evolution, the need to actively *help stem cell researchers make sense of public engagement* was identified and, in response, the project has developed strategic actions in capacity building and sharing of best practice in public engagement. Fig. 1 outlines the structure of the project in 2017.

A central mechanism for achieving these missions is the project's multilingual website, www.eurostemcell.org, (Fig. 2), which is founded in a systematic and collaborative approach to collating and 'packaging' stem cell and regenerative medicine information – from historical perspectives to synthesized contemporary knowledge and research updates. Core content is written in plain language, accessible to non-specialists, and reviewed by subject matter experts and, in some cases, a representative of the target audience (e.g. patient, teacher) prior to publication. All content is fully attributed, so that the author(s) and reviewer(s) of each article, and their expertise and affiliations, are clear to the reader – contrasting the knee-jerk fast output/response to research findings that can be prevalent in digital spaces.

Through working with multiple network members, EuroStemCell can offer 'synthesized commentary' on a given aspect of stem cell research rather than the single opinion of one research group. Consequently, a more complete, high quality, picture of the field can be built up in a single location, and can easily be found by different audiences and stakeholders. This approach has the additional benefits of reducing duplication of effort and dramatically increasing the reach of individual outputs. The website now has a foundation of high quality content that can be repurposed, remixed and distributed across multiple channels. EuroStemCell also supports development of targeted tools for public and schools engagement with stem cell research – often through partnership – and seeks to collate relevant engagement methodologies and activities and make them available for widespread use [5].

EuroStemCell has a 'hub and spoke' structure. The 'hub' team at the University of Edinburgh co-ordinates the project. The thirty-four current core partner institutions include the coordinating partners of many European Commission (EC) stem cell research consortia, and European national and regional stem cell networks. At the funding proposal stage these partners agreed to provide academic, in-kind and in some cases financial support for the project. The partners also use EuroStemCell as a route to disseminate their scientific outputs, where appropriate, and as a centralised resource for accessing training and tools for delivering public engagement activities. This reciprocal synergistic relationship provides incentive within the partnership. Each partner provides at least one senior scientist and one communications professional as key network contacts. Through and beyond the formal partnership, EuroStemCell's network extends to include organisations across Europe. Subject matter experts – scientists, ethicists, social scientists, clinicians, patient representatives and others – who are active in stem cell research and support the work of the project can be called on for comment and to write and review content. Most members of this 'Network of Expertise' have received EC or national stem cell research funding and met the criteria of these funders' rigorous review processes – providing an additional layer of trust and credibility. The entire project (summarised in Fig. 1) is enabled by the equivalent of two full time core staff located in a single site, within the MRC Centre for Regenerative Medicine at the University of Edinburgh, whose expertise includes public engagement, schools education, digital engagement, translation and science communication. These staff coordinate and manage all aspects of the project across the six themes.

3. History & evolution of eurostemcell.org

The website eurostemcell.org was launched in 2004, initially as a project website intended to serve a research consortium, funded under the European Commission's 6th Framework Programme (called *EuroStemCell I* herein). The goal of *EuroStemCell I* was to build the foundations for regenerative medicine, primarily through research in fundamental stem cell biology, but also through collaboration, training and outreach activities. The project's website included information accessible to non-specialist audiences, such as answers to frequently asked questions about stem cells and regenerative medicine.

The EuroStemCell website was launched at a time when claims that adult stem cells could turn into any other sort of cell in the body were prevalent in the literature – but were beginning to be disproven (see e.g. [8,9]) – and soon afterwards the discovery of induced pluripotent stem cells (iPS cells) rocked the biomedical research community [10,11]. At the same time there was growing awareness amongst academics in the stem cell field and wider publics of the complex and numerous social, and ethical dimensions of stem cell research [12–14]. Meanwhile, regulators and

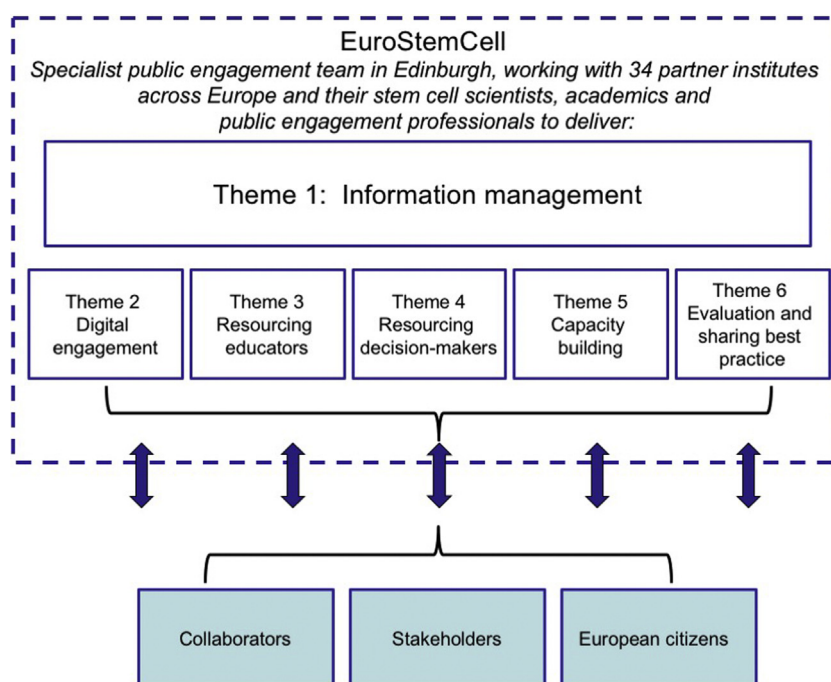


Fig. 1. Structure of the EuroStemCell project in 2017. The six main areas of work are represented as themes, the work under these themes is advised by small working groups from within the partnership. The collaboration with external stakeholders is represented as a two way process. The whole project is surrounded by a dotted line to represent the permeability of the project to external influences, ideas and trends.

policy makers were facing the need for new national and international regulatory systems to provide quality assurance, control, standardization and safety checks for cell-based therapies [15,16]. However, even those within the stem cell scientific community were struggling to develop a clear and consistent understanding of how stem cells work in the body. Increasingly, it was recognized that there was an unmet need for the coordinated provision of stem cell research information.

The decision to establish an outreach and communications programme within *EuroStemCell I* thus arose from an appreciation of the high hopes for development of new stem cell therapies, and of the emotive issues surrounding the stem cell field – including human cloning and the use of embryos for research. The project scientists recognized the public interest in their work and felt they had a responsibility, and were uniquely positioned, to bring synthesized understanding of this complex field into the public domain while addressing counterproductive misconceptions. By engaging with the public, including patients and their representatives, they could support informed decision-making around stem cell research and regenerative medicine – from questions of organ and tissue donation to treatment choices, funding and political decisions. It was acknowledged this engagement could also be important for the development of future stem cell-based therapies.

From 2004 to 2008 therefore, EuroStemCell developed an ambitious public engagement and outreach programme. The project team worked in collaboration with filmmakers to produce a series of short documentaries on the science and ethics of stem cell research – including the award winning ‘*A Stem Cell Story*’ [17]. These films were distributed via film festivals and on DVD, and were made freely available on the (then) relatively new platform YouTube. A public information section was established on the *EuroStemCell I* website – based on the questions consortium participants received from members of the public and from patients. The outreach and public engagement activities developed in this period were further informed by interaction with social scientists through the ‘Talking Stem Cells’ project led by Dr Sarah Parry at the University of Edinburgh, which aimed to investigate views and concerns

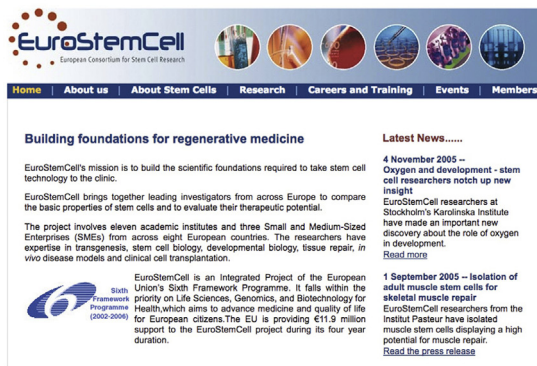
about stem cell research, and explore the scope for increasing public engagement in the developing field. This interaction – among other things – led to development of experimental public and schools events, and introduced the participating scientists to the concept of dialogical engagement [18], defined at that stage as “a window for stakeholders and non-stakeholders, scientists and non-scientists to hear the views of others while sharing their own: an opportunity for exchanging ideas and mutual learning” [18].

EuroStemCell I ended in 2008, but ongoing public interest in stem cell research was clear. Project partners continued to receive enquiries from patients and caregivers, and stem cell research was never far from the news headlines. In particular, the film ‘*A Stem Cell Story*’ received wide acclaim, at science film festivals, among teachers and educational resource providers,¹ and with other audience groups including patients, science funders and politicians. The 15-min film has now been viewed on YouTube over 320,000 times and has been watched for over 29,000 h during its lifetime.

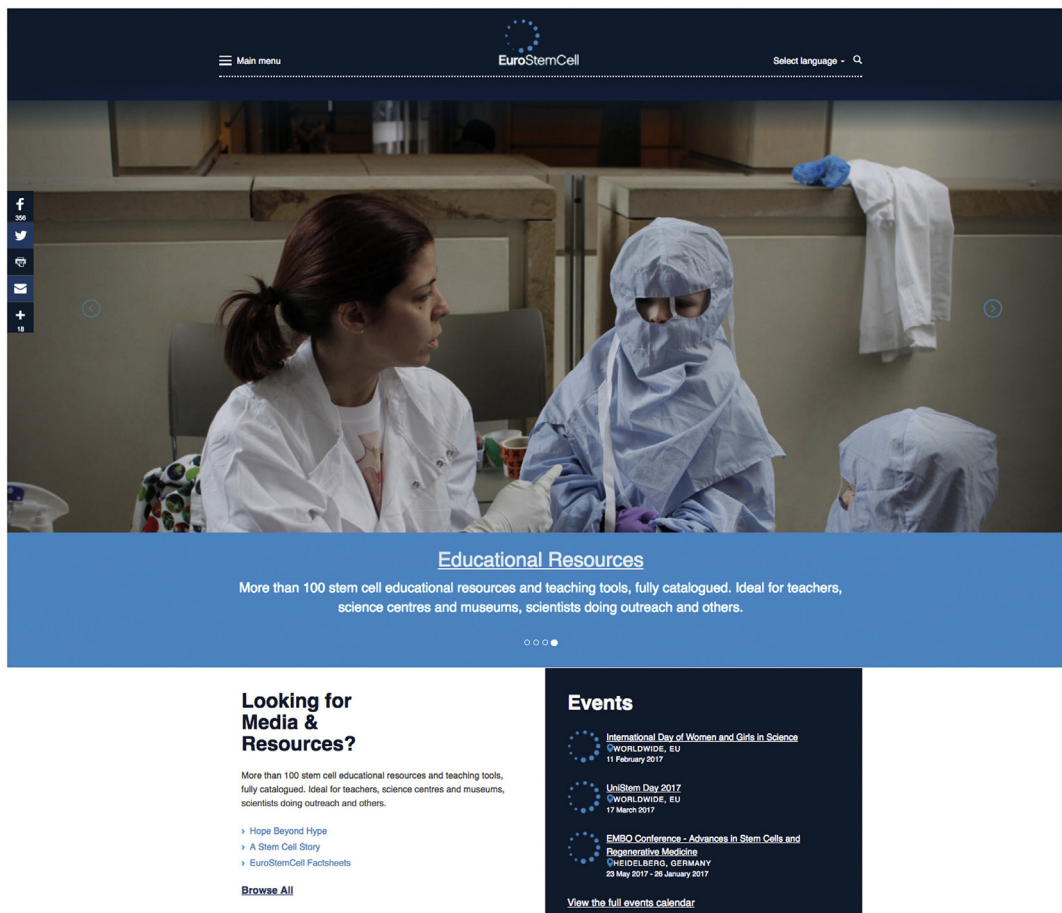
Project partners recognized an opportunity to develop a Europe-wide infrastructure for public engagement with stem cells and regenerative medicine that would allow sharing rather than duplication of effort and know-how. A decision was therefore reached in 2008, to our knowledge for the first time for a project of this type, to try to sustain the website and resources beyond the life of the original scientific research project. Redevelopment and expansion of the existing project website was initiated, supported initially by one existing and three new EU-funded research consortia. The goal was to put public engagement front and centre, helping European citizens find trusted, credible and up-to-date information about stem cell research and have the opportunity to engage with the wider research community. The latest digital technologies, including social media and a multilingual content management system,

¹ Best TV/video production, Tromsø Science Media Festival. Best short film, Cinema (Australia). In competition, Science Film Festival (Bangkok), BaKaFORUM 2007, Vedere la Scienza. Recommended by Scottish government agency Learning and Teaching Scotland as a tool for National Qualifications support.

a. EuroStemCell I, 2006



b. EuroStemCell II, 2016



c. EuroStemCell III, 2017

Fig. 2. The evolving look of eurostemcell.org, 2005–2017. The latest iteration of the website was launched in December 2016.

as well as evolving website design, all supported these objectives (Fig. 2).

Additionally, a new direction emerged for the work of the project. Progress in fundamental science and anticipation around the development of new stem cell therapies created conditions in which some organizations could start selling unproven treatments directly to patients with incurable conditions. The advertising of these so called 'stem cell treatments' was predominantly undertaken online and via social media. This phenomenon entered scientific academic discourse in 2008–9 [19] along with attempts to provide clear guidelines to address some of the issues [20].

EuroStemCell responded by broadening its objectives to support informed decision-making about the clinical use of stem cells. This included information provision on medicine and stem cells (Table 1, Section 3), face-to-face discussion events with non-specialists, and researcher training and support on patient- and public- engagement (Table 1, Section 5). In addition, in-depth articles were published on the EuroStemCell website, highlighting the clinical trials process, national and European regulatory processes, private stem cell clinics, stem cell tourism and for-profit clinical trials [6] – all optimised for search (see Section 5.1.3 for further detail).

Table 1
Structure of EuroStemCell website and rationale.

Website Section	Audience	Rationale
Section 1: Explore Stem Cells [4]	Formal or informal educationalists, general interest groups i.e. people in full-time education, general interest European citizens, media professionals or scholars from other disciplines.	Providing access to current and credible information on stem cells, the applications of them in research and healthcare, and the social, moral and ethical implications of their use. Information is synthesised from many sources, written in clear language in summary and longer form. Further information provided and provenance of information transparent (e.g. writers, reviewers, specific research projects, research papers). Filters are used to allowed people to search for information useful to them.
Section 2: Education [5]	Formal or informal educationalists, public engagement professionals, scientists involved in public engagement or outreach activities.	A repository of activities, games, films, materials and resources developed by EuroStemCell or others. Collated with the aim of reducing duplication of effort and increasing the quality of educational engagement about stem cell research. Filters are used to allowed people to search for resources suitable for their needs.
Section 3: Medicine and Stem Cells [6]	People affected by conditions, their carers, patient advocacy groups, condition specific charities, policymakers and healthcare professionals.	As section 1 above but with focus on specific conditions. In addition, specific articles address the current applications of stem cell therapies, how to get involved in stem cell research through clinical trials or patient registries, making decisions regarding treatment offers and issues around stem cell tourism.
Section 4: About EuroStemCell [7]	Partners, funders, collaborators, future collaborators, associated projects and other interested parties.	This section provides information about the structure of the project, how it is funded, the network, the people and projects involved and the history of EuroStemCell. It aims to help people assess the credibility, provenance and scope of the project.
Section 5: Engagement Practitioner Platform (not publicly available)	Partners and key collaborators.	The section contains content specific for partners or public engagement practitioners. It aims to facilitate efficient functioning of the project and to share best practice on the public engagement with stem cell research. It contains: project documents such as annual reports and evaluation reports; a EuroStemCell Handbook which contains editorial frameworks and guidance for partners; resources on public engagement and evaluation and case studies or reports of partner engagement activities.

EuroStemCell received its first stand-alone funding from the European Commission's Seventh Framework Programme in 2010, as a coordinating and support action. By this time over 86,000 people per year were visiting the site, and a smaller but significant number were accessing the project or its partners via other channels including film screenings, public events, social media, open days and schools engagement activities. Audience research performed by the professional science communicators on the project using mixed methods (i.e. online surveys, informal feedback and formative discussions with internal and external partners) identified provision of information as a major priority. In response, a series of fact sheets, FAQs, and commentaries on a wide range of topics in stem cell biology, regenerative medicine and related societal issues were developed, written in plain language to a defined template and reviewed by experts (usually from within the project partnership) in the relevant area prior to publication (Table 1, Sections 1 and 3). Specifically to serve the needs of science communicators, educators and scientists – and at their request – a toolkit of educational materials, e.g. films, comics, lesson plans, games, activities, animations and activities, was developed in partnership with other projects. These and other relevant resources identified through interactions with collaborators, partner projects or stakeholders groups were catalogued in a directory that contained over 100 entries (Table 1, Section 2). These new engagement tools were designed for use in both face-to-face engagement activities (i.e. open days, school visits, patient visits to laboratories, science festivals) and online (e.g. videos, interactive comics, animations), with EuroStemCell offering training and support for researchers in public engagement and in using these materials in public settings. The public engagement training provided by EuroStemCell is usually in the form of sessions scheduled into the programme of scientific events like annual meetings, conferences or summer schools.

Multilingual functionality was identified as an essential development, and was added to the website from 2011 – translating the interface and key content into English, French, German, Italian, Spanish, and Polish and so making the site accessible to more than 80% of Europeans in their first or second language. Social media channels including Twitter, Facebook and YouTube were used to

support all communication efforts, providing supplementary conversation and dissemination platforms, while raising the profile and extending the reach of the website, resources and direct public engagement.

In an audience evaluation, in the form of an online survey disseminated through our partnership and networks carried out by a professional external evaluator in 2011, 95% of respondents (n = 240) felt the website provided reliable information and 86% said they would recommend it to their colleagues and friends. Underpinning all of the project's actions was a strong ethos of collective ownership and development. By 2011 more than 120 scientists, ethicists, legal experts, science communicators and social scientists from all over Europe had contributed content to the website, with many more participating in the translation effort.

The project, now in its third iteration, is still funded by the European Commission as a co-ordinating action in the Horizon2020 programme. The website has had over 200 contributors – scientists, social scientists, ethicists, anthropologists, economists, clinicians, patient advocates, lawyers, educationalists, public engagement specialists, writers, film-makers, artists and translators (see Table 1 and Section 4. The collaborative model). In 2016 it received over 1.3 million unique visitors annually from all over the world (Source: website analytics; see Fig. 3). Many of the original rationales for the work still exist; for example, due to the challenges of regulating stem cell therapies and the absence of globally harmonized regulations, unproven therapies continue to be offered in some territories [21]. Indeed, the marketing of unproven stem cell therapies directly to consumers has only become more contentious and still poses a significant threat to the legitimate development of cell-based therapies [22,23].

4. The collaborative model

EuroStemCell is rooted in the research community and its partnership model has been instrumental in establishing a project of sufficient breadth and credibility to stand the test of time. The project's credibility is strongly related to the time freely given by world-leading experts in the field. From the outset, EuroStem-

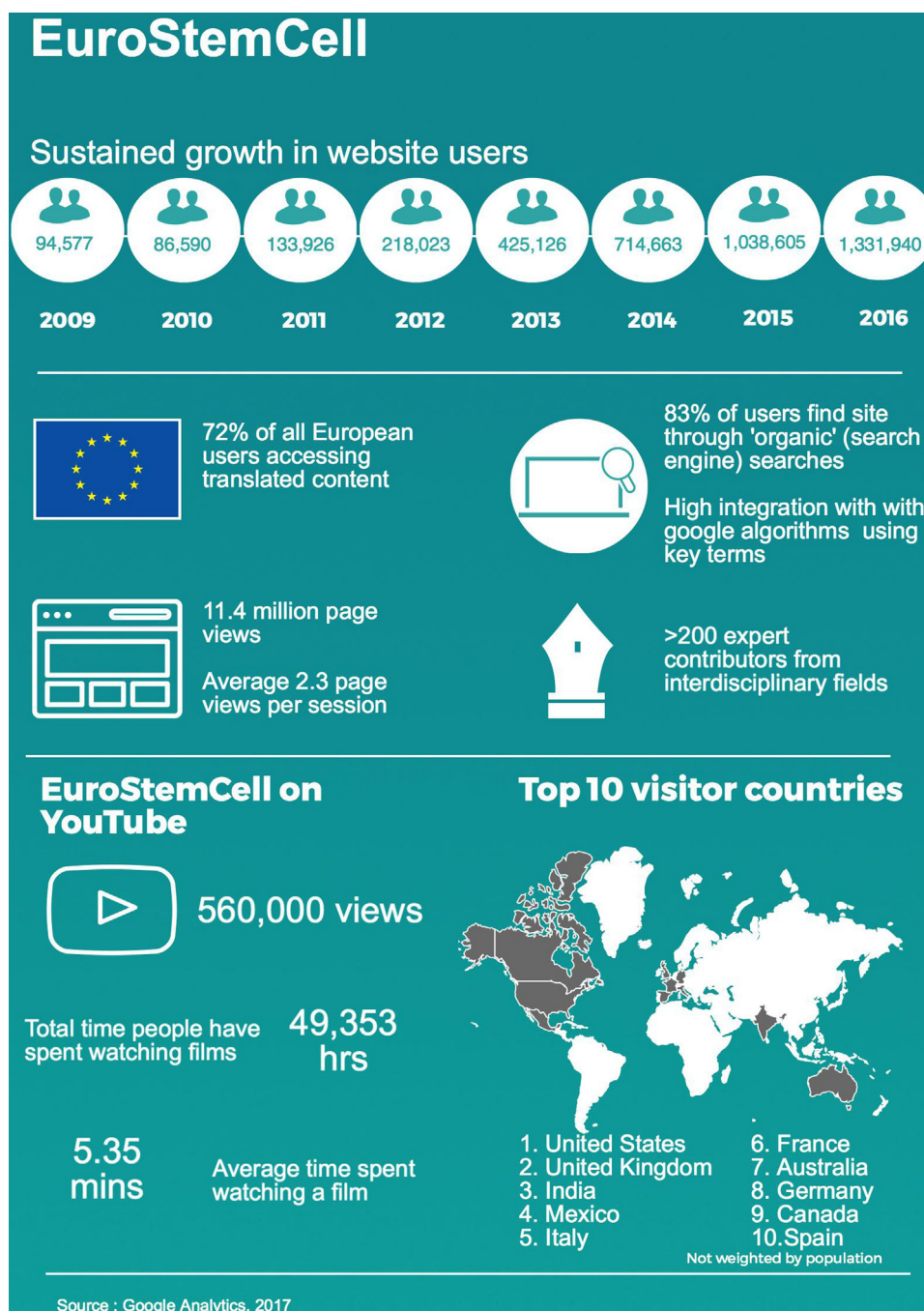


Fig. 3. Website growth and social media usage 2009–2016 (source website analytics, 2017).

Cell had high-level support from a small number of world-leading senior researchers and some key interdisciplinary partners in the social sciences and bioethics fields. As the project has grown, the scope of expertise represented by the project has widened [24] allowing EuroStemCell to address the social, moral and ethical contexts of the research as well as the science. The interdisciplinary aspect of the project is of growing importance as the science progresses closer to clinical translation and adoption by healthcare providers, and accordingly, fostering appropriate collaborations has been one of the project's intentional goals from its early stages of development. Constant evolution is key for maintaining the credibility of the project and its outputs as the sector continues to develop. Fig. 4 models the reflexive approach that drives the actions

of EuroStemCell, showing the interactions that EuroStemCell brokers, whilst representing the agency and movement of the multiple stakeholders with whom the project works.

5. The EuroStemCell project in 2017

5.1. EuroStemCell: core mission and objectives

EuroStemCell's core original mission was to help European citizens make sense of stem cells and evolved to encompass helping the stem cell research community make sense of public engagement. The project is clearly positioned as an information and resource provider, and broker of engagement between many different audi-

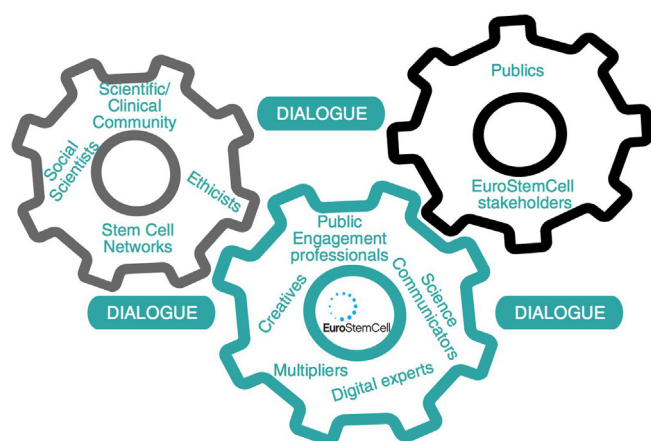


Fig. 4. EuroStemCell's collaborative approach. Schematic representation of the many dialogue-based interactions underpinning and promoted by EuroStemCell. 'Multipliers' refers to key organizations and initiatives that can expand the reach of the project, for example, patient advocacy groups, teacher trainers and policy networks.

ence groups. These functions depend on its maintaining a position of trust among its stakeholders and users. Therefore, it has a policy of openness, underpinned by attribution of all content, and additionally has developed a clear non-lobbying stance: although members of the network may have strong views and take lobbying actions, this is never a function of the project itself. Overall therefore, the project presents a holistic approach to public engagement in its specialist field, which is delivered through five core strands of work outlined below.

5.2. Developing a European network on public engagement with stem cell research

The EuroStemCell project exists fundamentally as a network of stem cell research institutes, networks and organisations with key contacts (senior scientists/academics and engagement professionals) in each of these entities. Network members fulfil several roles for EuroStemCell. First, through the project's working group structure, small groups of partners advise and ratify the work which is carried out in each area of the project (see Fig. 1). These working groups prioritize topics for consideration and provide expertise for review or commentary on those topics. Expertise is also drawn from outside the stem cell research community. Second, they provide access to the research – through the provision of researchers for engagement actions and by providing access to research findings or clinical trial information as they are released. Finally, they act as national champions for the consolidated outputs of the EuroStemCell Network, extending the outcomes of the project into new localities and networks.

At the practical level, much of this is achieved through regular email requests to partners for new research findings or resources, small working groups (as mentioned above) and a smaller number of structured strategic discussions at EuroStemCell workshops, consortia scientific meetings or summer schools. For actions involving specific stakeholders – for instance people affected by conditions and their carers – small focus groups (either face-to-face or online) are held with representatives of these stakeholders in order to formatively shape the action. These approaches enable a coordinated response to dissemination of, and commentary on, advanced understanding of stem cell research findings and developments in regenerative medicine. Rather than each research centre or institute producing their own website and building up a local audience, each contributes to a broader effort designed specifically for European citizens through the EuroStemCell website.

5.3. Collaborative development and dissemination of resources for use in education and in direct and online public engagement

The availability of EuroStemCell's resources online means that development and production work undertaken by one group can be used by other members of the network and, as discussed above, that the resources can easily be found by different audiences and stakeholders. EuroStemCell is committed to promoting and sharing good practice in resource development. For instance, outputs of the project itself are co-produced and prototype-tested with target audiences (e.g. in classrooms or with teachers) to ensure they are relevant, accessible and engaging and, in the case of educational resources, curriculum-compatible [25]. We have found that co-development of resources together with target audiences, and participation in face to face engagement activities around specific topical issues is essential, as it grounds all of the work of the project in dialogical engagement with target audiences. An increasing focus has become the provision of resources to support those who have to make decisions regarding stem cells and regenerative medicine. An important strategy that has evolved from this work is collaboration with 'multiplier' organizations, for instance educational resource providers (e.g. Scottish Secondary Education Resource Centre, STEM Learning, TES Resources [26–28]) and patient advocacy organizations (e.g. Parkinsons UK, Scope [29,30]) and, where appropriate, media organisations such as the Science Media Centre, which increases the reach of tools and resources developed by the project and also allows resource validation and/or accreditation by organizations respected by the intended end-user.

5.4. Digital engagement to maximize EuroStemCell's reach and impact

A project with a pan-European remit and limited resources can only reach a small group of stakeholders face-to-face and therefore a strategic approach is needed. Digital channels open the possibility of reaching a much larger and more diverse audience, wherever they are and in many cases in their own space.

High quality content that can be translated, repurposed, remixed and distributed across multiple channels is the backbone of our digital engagement strategy. There is, however, a significant challenge in structuring content to reach the wide range of digital audiences that EuroStemCell aims to engage. EuroStemCell categorizes these audiences into three groups: general interest non-specialist, informed non-specialist, and specialist communities (see Table 2 for examples). These categories allow the project to meet the needs of a wide variety of audiences. They function to aid structuring of the information behind the scenes, while the 'visible' structure represented on the website is organised to retain flexibility and appeal to diverse audiences (see Table 1), using tagging and metadata to allow content to surface via appropriate filters. Dynamic provision of new and updated website content for each of these audience groups is key to the project's success, as is its availability in the six most commonly spoken languages in Europe (English, French, German, Italian, Spanish, and Polish) [31].

Topical, relevant, accurate content is more likely to rank highly in online searches and be found. Supporting this, EuroStemCell's platform and resources (including factsheets and digested reads) are optimized for search using best practices laid out by the World Wide Web Consortium (W3C), making it easier for search engines like Google to index the content. EuroStemCell consequently ranks well in Google (and other i.e. Yahoo and Bing) searches. To aid this the project pays regular and close attention to search engine optimisation (SEO) strategies incorporating current best practices. Of the 1.3 million users of the website in 2016, 82.7% of them found the

Table 2
Summary of EuroStemCell's evolving learning about audience needs.

Audience	Example	EuroStemCell learning regarding needs	Provision
General interest non-specialists	Families, Community groups, school students, European citizens	<ul style="list-style-type: none"> - Accessible approaches, built on the dual foundations of plain English and scientific review - Succinct, synthesized, collated and overarching subject-specific information on research developments and clinical progression - Credible, reliable and transparent information sources - Opportunities for discussion of ideas and questions, including online, via social media, and face-to-face at events 	<p>Use of multi-media.</p> <p>Co-production and collaboration with creative industry professionals such as artists, writers, graphic artists, sculptors and film-makers.</p> <p>Writers and reviewers who can engage with senior scientists and other primary information providers to help provide the 'bigger picture' of stem cell research.</p> <p>Clear procedures regarding the timely updating of research/clinical developments that are visible to website users.</p>
Informed non-specialists	People affected by conditions, care-givers, teachers, school students, healthcare professionals, media professionals, policy-makers, parliamentarians	<ul style="list-style-type: none"> - Lay summaries of research papers - Succinct, synthesized, collated and overarching subject-specific information on research developments and clinical progression - Credible, reliable and transparent information sources - Opportunities to talk about and discuss their thinking, ideas and questions - Clear information on how to get involved with the research community - Multi-faceted approaches, such as online; face-to-face; interdisciplinary; small forums; conferences; out-reach and in-reach 	<p>Lay summaries of individual research papers in areas of key interest.</p> <p>Resource review processes that include/involve science communicators, educationalists and people affected by conditions.</p> <p>Writers and reviewers who can engage with senior scientists to help to provide the 'bigger picture' of stem cell research.</p> <p>Clear procedures regarding the timely updating of research/clinical developments that are visible to readers/website users.</p> <p>A dialogic approach to engagement events and the promotion of that approach amongst the EuroStemCell partnership.</p>
Specialists	Regulators, members of the academic research community, and stem cell companies	<ul style="list-style-type: none"> - Timely responses to current priorities - Holistic approach to topics rather than single issue or single viewpoint - Access to interdisciplinary networks, stakeholder organizations and specific experts 	<p>Information that has had multiple reviewers.</p> <p>A needs-based approach to subject matter.</p> <p>Multi-disciplinary approaches such as combining social science, economics, bioethics approaches with science.</p> <p>Well coordinated contacts and networks management.</p>

site through 'organic' searches – they entered terms² into a search engine and this led them to eurostemcell.org. The importance of this cannot be overstated: when people are looking for information about stem cell research they find eurostemcell.org.

5.5. Building capacity within the scientific community to participate in public engagement

EuroStemCell provides a mechanism to facilitate the sharing of learning amongst professionals in intermediary roles (such as communication officers, outreach officers and public engagement

practitioners), by facilitating networking, providing training and resources (see Table 1, Section 5), and disseminating the outputs of workshops, conferences and other events. These actions are made possible by the co-ordinating role of the project staff and by extra expertise drawn in from the partnership. The need for work in this area was recognized relatively early in the project's development (during the 2008–2010 phase) as it became apparent that communications, engagement and outreach officers are key 'influencers' of the quantity and quality of engagement actions from a given institute. In addition the EuroStemCell project staff facilitate yearly 'sharing best practice in communicating about stem cell research' workshops in different European cities for stem cell-related communication/outreach professionals. This has become an increasingly important mechanism for supporting partners in participating in the engagement/communication effort surrounding

² Such as "stem cell therapy" "embryonic stem cell research" "what are stem cells used for?" "use of stem cells" Source: website analytics, 2017.

stem cell research and increasing the impact of the EuroStemCell project.

5.6. Embedding evaluation into all levels of the project

The actions detailed above have allowed for the promotion of the role and importance of evaluation in public engagement amongst the researchers who participate in public engagement activities, a theme which is explored in detail elsewhere in this edition [32]. Evaluation is used regularly to monitor user experience of, and viewpoints regarding, the project. A core project ethos is a timely and structured response to the findings of this evaluation work, resulting in changing mode of action or direction of activity in order to strengthen the project. For example, through evaluation work with patient organisations we discovered that basic research, as well as clinical research, was of interest to them. A second discovery was the negative impact of pages and text in English on translated/non-English elements of the website; the website redevelopment undertaken in 2016 directly addressed this.

The project uses an evaluation framework developed in collaboration with a professional external evaluator, to assess project outcomes from the perspectives of: the individual or end-user, network stakeholders (principally organizations or networks or their representatives), and partners (for example the scientists, social scientists, ethicists, public engagement practitioners and communication officers who are 'official' partners within the EuroStemCell project) (see Fig. 5). This takes the form of online surveys (end-users and stakeholders), interviews (partners) and semi-structured focus groups (partners) at project meetings or web conferences. This is coupled with internal monitoring of the project, for example using website analytics to monitor online activity, along with case studies and logging the number and nature of engagement activities across the partnership. These evaluations have revealed important information regarding the reach and impact of EuroStemCell but have also provided evidence of impact that have been used for Research Excellence Framework case studies for the University of Edinburgh and in funding applications.

The evaluation actions have revealed several findings: first, the information and resources provided by EuroStemCell are valued by the different types of stakeholders, and EuroStemCell is established as a source of reliable, accessible, credible and up-to-date information. Second, the translation of the website has been vitally important to the reception and reach of the project across Europe and beyond. Third, EuroStemCell now has a large digital footprint that allows extremely broad dissemination of resources and supports wide-ranging connections with diverse stakeholders. Fourth, EuroStemCell is brokering and building new networks and partnerships amongst the scientific community, the stem cell public engagement community and between different disciplines. This fosters the effective sharing of best practice in stem cell research public engagement across Europe and has contributed to development of new research projects and initiatives. Examples are:

- A stem cell research 'Wikithon' initiative, initially developed by one EuroStemCell partner [33] then disseminated by EuroStemCell to all partners along with associated guidance material. Wikithons are concerted actions that provide training and support for the editing of wikipedia to increase the quality of online information, and require minimal training and time commitment.
- Participation of EuroStemCell partners in UniStem Day – an initiative pioneered and led by the University of Milan [34]. UniStem Day currently represents the largest single day focussed on engagement of young people with stem cell research in Europe. Initially run only in Milan, with an audience of a few hundred, in 2017 over 70 Universities across 7 European countries engaged with over 27,000 high school students on a single day. EuroStem-

Cell was instrumental in the growth of this initiative, through its dissemination and coordination functions.

6. A public engagement perspective

6.1. Public engagement in the context of EuroStemCell

The National Coordinating Centre for Public Engagement defines public engagement as “a two-way process, involving interaction and listening, with the goal of generating mutual benefit” [35]. However, as public engagement itself is a developing field, alternative definitions exist [36–39] and it is important that each initiative uses an operational definition of ‘public engagement’ suitable for its own specific context. EuroStemCell draws on work by Parry et al. [18] to use a definition of public engagement that includes:

- *co-production with partners of tools and resources, with the objective of providing knowledge exchange channels in to, as well as out of, the stem cell research community;*
- *fostering collaboration between interdisciplinary stakeholders; and,*
- *empowering both the publics and the scientific community to participate in dialogue, deliberation and policymaking surrounding the complex issues in this field.*

Provision of scientific information has been the subject of much discourse within the public engagement sphere. The debate centres on the need to move beyond the now outmoded ‘deficit’ model of communication,³ which uses information provision as a central mechanism, with an underlying assumption that information provision will generate public acceptance [40]. Indeed, Mohr and Raman [41] and others [42] have highlighted that more dialogue-based⁴ perspectives are required, in order that deeper, more complex, and potentially more powerful public engagement with research is achieved.

EuroStemCell's perspective is that information provision has an important role in public engagement. It facilitates conversation, rather than dictating its outcome; in other words, information provision enables “manifold perspectives, visions and values that are relevant to the science and technologies in question” – as suggested by Mohr and Raman to be one of the goals of public engagement [41]. Information brings relevance and context to the conversation with audience groups that have been integral to the development of EuroStemCell outputs. In this context, the intended outcomes of information provision are empowerment, mutual learning, participation and dialogue. The early adoption of a dialogic (or reciprocal) approach to knowledge-building and sharing has been critical to the success of EuroStemCell, has been actively fostered, and will continue to develop.

6.2. The spectrum of public engagement: playing our part but not yours

Fig. 6 summarizes the EuroStemCell approach, which regards information provision as an important foundation but not a replacement for more nuanced and complex forms of public engagement. This framework is supported by research into public engagement, albeit using different terminology. Hetland [43]

³ The deficit model in this context is defined as a process of transmission of information from the scientific community to non-specialists with the outmoded assumption that understanding will result in acceptance, trust in, and potentially approval of, that area of science.

⁴ Dialogue is defined here as a two-way interaction involving listening, transmission and mutual participation by both/all parties. In dialogue, the perspectives, experience and approaches of all parties are valued, the emphasis is on deliberation and mutual education rather than persuasion.

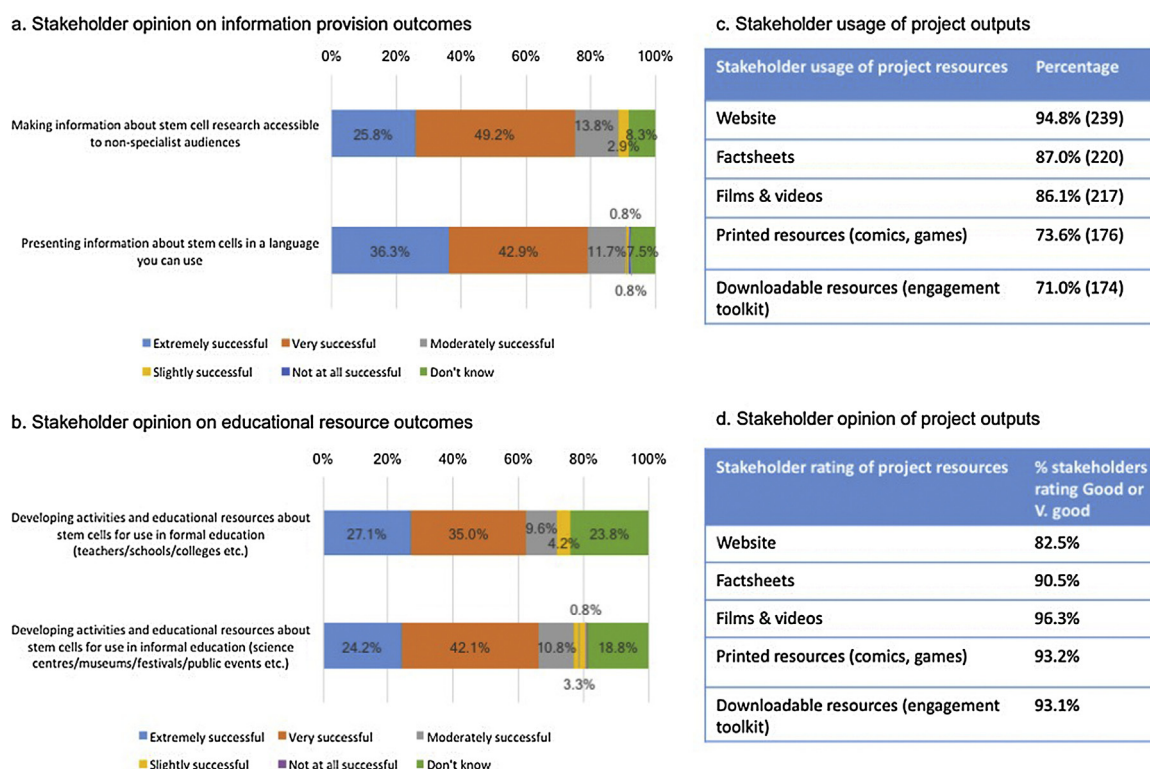


Fig. 5. Stakeholder evaluation of the EuroStemCell project. The data presented form part of a stakeholder evaluation report completed in June 2016, and show opinions on how well EuroStemCell was then achieving its stated outcomes in relation to information provision and educational resources (**a, b**); how stakeholders use the individual resources produced by the project (**c**); and their rating of that resource (**d**). Stakeholders are defined here as partners in the EuroStemCell network or project; they represent the multipliers for the actions of the project. They are not the 'end-users' of the resources, although it is acknowledged there is overlap. For example, a representative from a patient advocacy organization would be termed a 'stakeholder' and included in this evaluation, whereas the person affected by the condition would be defined as the end-user and would be included in a separate evaluation action. This evaluation work was undertaken to inform the redevelopment of the website which was launched December 2016. Data are based on 240 respondents from 15 countries within the network.

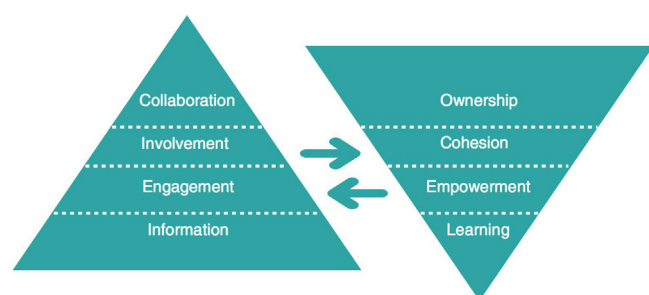


Fig. 6. Spectrum of public engagement. Representation of the spectrum of activity that represents public engagement with research, showing associated possible outcomes. Information is represented as foundational to other modes of engagement.

concludes that the goal of public engagement is **not** to evolve from dissemination of research via dialogue about research to public participation in research [43]. Rather, they challenge the idea that these three models form a hierarchy, and conclude that there is a place for all three in public engagement with science [43].

As a project, we co-ordinate the flow and exchange of information in a timely and accessible manner, with the primary aim of stimulating engagement and two-way communication between the scientific community and other communities about stem cell research. A useful means of conceptualizing this approach to information provision is as follows: at one level, EuroStemCell views its role as providing 'information for dialogue'; however, because an ethos of co-production underpins all of the information-provider work of the project, this can be extended to 'information as dialogue'. A recent Canadian study comments on the value of this approach [44], revealing that with access to well-crafted online

communications about iPS technology, lay citizens could provide nuanced and insightful advice to policy makers. Longstaff et al. [44] also highlight the importance of accessible, accurate and up-to-date information on stem cell research and conclude by encouraging the stem cell community to continue to make their work widely available in online formats suitable for non-specialist communities. This approach is further supported by other smaller scale studies such as the Patient's Participate! Project, which identified 'digested reads' of primary research materials as a priority for people affected by conditions [45]. The dramatic increase in eurostemcell.org and associated social media usage also speaks to the validity of this approach. In the context of stem cell research, developmental biology and regenerative medicine, EuroStemCell therefore fulfils a part of the public engagement imperative but does not provide the whole. There is space in this arena for others in the scientific community to also take up the mandate with their own approaches, expertises and ideas.

7. The future necessity for ongoing public engagement with stem cell research

Initially, advances in embryonic stem cell research caused debate and a rethinking of policy and regulations due to the use of embryos for research and the potential for human reproductive cloning. Some thought that with the discovery of iPS cells, ethical debates were resolved, but this was not the case [12,21]. iPS technologies have simply added to the ethical matrix, revealing more complexities in the ethical, social and moral dimensions of stem cell research. Rather than becoming less contentious over time, as both science and clinical translation progress, new ethical issues

are often revealed that must be addressed through national and international policies [21].

Within this societal context, and in light of the high public profile of stem cell research, sustained and continued high-quality public engagement with stem cell research is vital [21,46], especially as the nature of patienthood, health, patient activism (efforts to change the ‘norm’ in healthcare provision) and risk evaluation evolve within the digital context [47]. This necessitates public engagement with stem cell research that spans the whole spectrum of engagement activity [18, Fig. 6], including the two-fold role EuroStemCell can play in information provision for digital engagement and capacity building in the scientific and science communications communities. However, EuroStemCell’s approach of coordinated provision of synthesized, co-produced and evaluated information from the scientific, social science, and bioethical communities is part of a much bigger picture and indeed is only one aspect of the EuroStemCell project. Looking to the future, the project is now embarking on several large digital initiatives that will bring together different areas of expertise to help forge new ways of thinking about how ‘decision makers’ can be supported and resourced. Clearly, deliberation and decision-making are multi-factorial issues, and once again EuroStemCell seeks to proactively play a part whilst acknowledging that our role is only part of the process [44,48]. The involvement of many interdisciplinary sectors supports complex, meaningful and holistic engagement – a necessity as this fast-moving field continues to innovate and evolve.

Our experience to date with the EuroStemCell project has taught us that there is a strong appetite for engagement amongst the many and diverse publics, and that by working in partnership with networks and multi-stakeholders, it is possible for a relatively small project to achieve large international reach. Our hope is that others in the scientific community also take up this mandate to provide co-ordinated and collaborative public engagement efforts in their own fields.

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